Periprocedural Intravenous Heparin During Endovascular Treatment for Ischemic Stroke

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Patient-reported outcomes of adults with congenital heart disease from eight European countries: scrutinising the association with healthcare system performance

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Abstract

Background: Inter-country variation in patient-reported outcomes of adults with congenital heart disease has been observed. Country-specific characteristics may play a role. A previous study found an association between healthcare system performance and patient-reported outcomes. However, it remains unknown which specific components of the countries' healthcare system performance are of importance for patient-reported outcomes.

Aims: The aim of this study was to investigate the relationship between components of healthcare system performance and patient-reported outcomes in a large sample of adults with congenital heart disease.

Methods: A total of 1591 adults with congenital heart disease (median age 34 years; 51% men; 32% simple, 48% moderate and 20% complex defects) from eight European countries were included in this cross-sectional study. The following patient-reported outcomes were measured: perceived physical and mental health, psychological distress, health

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behaviours and quality of life. The Euro Health Consumer Index 2015 and the Euro Heart Index 2016 were used as measures of healthcare system performance. General linear mixed models were conducted, adjusting for patient-specific variables and unmeasured country differences.

Results: Health risk behaviours were associated with the Euro Health Consumer Index subdomains about patient rights and information, health outcomes and financing and access to pharmaceuticals. Perceived physical health was associated with the Euro Health Consumer Index subdomain about prevention of chronic diseases. Subscales of the Euro Heart Index were not associated with patient-reported outcomes.

Conclusion: Several features of healthcare system performance are associated with perceived physical health and health risk behaviour in adults with congenital heart disease. Before recommendations for policy-makers and clinicians can be conducted, future research ought to investigate the impact of the healthcare system performance on outcomes further.

Keywords

Healthcare system performance, heart defect, congenital, health services accessibility, patient reported outcome measures

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Introduction

As a result of an increased life expectancy, the population of adults with congenital heart disease (CHD) is growing exponentially.[1, 2] As a consequence, increased healthcare use has been observed, placing an additional burden on current healthcare systems worldwide.[3] Hence, healthcare systems across countries are challenged to meet the needs of this patient population, and more specifically, to reach satisfactory outcomes in adults with CHD.[4] As a result of increasing attention for person-centred and comprehensive care, interest in assessing patient-reported outcomes (PROs) is mounting.[5, 6] PROs are 'measurements based on a report that comes directly from the patient about the status of a patient's health condition, without amendment or interpretation of the patient's response by a clinician or anyone else'.[7] PROs have been shown to be of clinical significance, as they are independent predictors of mortality, cardiovascular events, hospitalisation and costs of care in cardiovascular patient populations.[8, 9]

Prior research has demonstrated a substantial inter-country variation in PROs of adults with CHD around the world.[10] For example, samples of patients from Australia had a mean quality of life of 82.1 on the linear analogue scale (0–100) and a sample from Japan had a score of 71.6.[11] It has already been demonstrated that patient characteristics, such as sex, age, educational level and New York Health Association (NYHA) class partly explain variation in PROs.[10, 11] At a country-level, standard of living and healthcare system characteristics are known predictors of PROs in adults with CHD.[10] One of these studies indicated that overall healthcare system performance, as measured by World Health Organization (WHO), was associated with the perceived health of adults with CHD. In general, policy-makers and healthcare administrators are increasingly interested in assessing the performance of their healthcare systems.[12] Measuring performance is important to identify high and low-quality service delivery, to design healthcare system reforms, to protect patients and payers, and to decide on appropriate investments, all with the overarching goal of improving quality of care.[12] Access to care, a component of the overall healthcare system performance, is an important variable that has been associated with healthcare financing and outcomes.[13]

The Andersen behavioural model of health services use is a theoretical framework that was developed in the late 1960s, aiming to facilitate the understanding of which factors influence patients' use of healthcare services.[14] With the growth of supporting empirical evidence, this model has expanded.[15] In the latest version of the model (see Figure 1), healthcare system organisation, including performance of the healthcare system, is considered to be a contextual characteristic that determines healthcare use and patient outcomes.[15] Indeed, the model assumes that contextual characteristics at the macro level are both directly and indirectly associated with patient outcomes (i.e. perceived health and quality of life) and that these relationships can be bidirectional. Little research has been undertaken, to date, to confirm this presumed relationship.

In recent decades, international agencies (e.g. WHO, Organization for Economic Co-operation and Development (OECD) and Health Consumer Powerhouse) have made efforts to capture and compare the overall performance of the healthcare systems of different countries. However, it remains unknown which components of countries' healthcare system performance are associated with PROs in adults with CHD. Therefore, in this study we aimed to investigate the relationship between components of healthcare system performance and PROs in adults with CHD.

Methods

The present study is part of a larger project entitled 'Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International

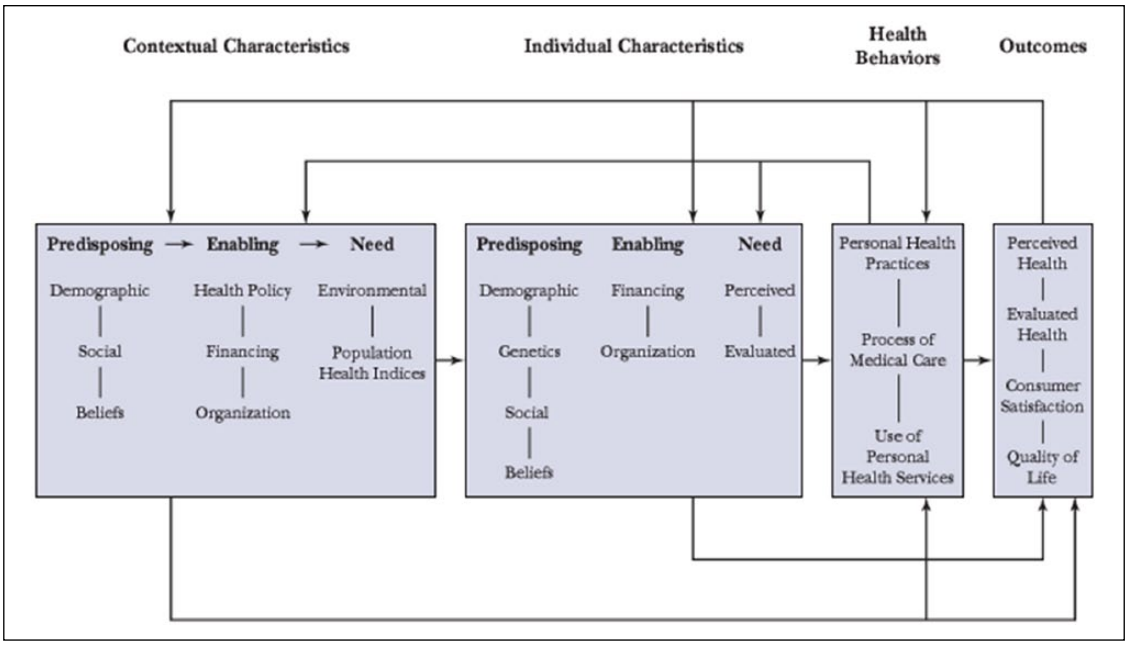

Figure 1. Andersen behavioural model of health services use, sixth revision.[15] Permission for reproduction was obtained from John Wiley and Sons.

Study' (i.e. APPROACH–IS). This research project included 4028 adults with CHD from 15 countries comprising five continents around the globe.[10, 11, 16] For the current analyses, we included all European countries participating in APPROACH–IS: Belgium, France, Italy, Malta, Norway, Sweden, Switzerland and The Netherlands, because uniform indices of performance of European healthcare systems (i.e. Euro Health Consumer Index (EHCI)[17] and Euro Heart Index (EHI))[18] were available for these countries.

Patients were eligible if they met the following criteria: (a) diagnosis of CHD, defined as 'a structural abnormality of the heart and/or intra-thoracic great vessels that is present at birth and of actual or potential functional significance';[19] (b) aged 18 years or older; (c) CHD diagnosis established before the age of 10 years (i.e. to warrant sufficient experience of living with CHD); (d) continued follow-up at a CHD centre or included in a national/regional CHD registry; and (e) possessing physical, cognitive and language capabilities required to complete self-reported questionnaires. Exclusion criteria were: (a) prior heart transplantation and (b) idiopathic pulmonary arterial hypertension.[16] Eligible patients received a questionnaire package by mail or during an outpatient clinic visit. Data collection ran from April 2013 to March 2015. The rationale, design and methods of APPROACH–IS have been detailed in a previous paper.[16]

The study was approved by the institutional review board of the university hospitals Leuven/KU Leuven Belgium (the coordinating centre) as well as the local institutional review boards of participating centres when required. All participants provided written informed consent to participate. The investigation conforms with the principles outlined in the Declaration of Helsinki.[20]

Measures

Data on four domains of PROs were assessed using self-report questionnaires: (a) perceived physical and mental health status using the 12-item Short Form Health Survey;[21] (b) psychological distress using the Hospital Anxiety and Depression Scale;[22] (c) health behaviours using the Health Behaviour Scale – Congenital Heart Disease;[23] and (d) quality of life using a linear analogue scale. Further details on the measures and their psychometric properties can be found online in the Supplementary material (Supplementary Table 1).

Healthcare system performance

Healthcare system performance of the participating countries was operationalised using the EHCI 2015[17] and the EHI 2016,[18] both developed by the Health Consumer Powerhouse.

The EHCI, which is published annually, measures and ranks the performance of healthcare provision of 35 European countries.[17] This index consists of a set of 48 indicators, which are divided into six subdomains: (a) patients' rights and information; (b) accessibility; (c) outcomes; (d) range and reach of services provided; (e) prevention; and (f) pharmaceuticals. More information about these subdomains can be found in Supplementary Table 2.

Table 1. Demographic and medical background variables in 1591 adults with congenital heart disease in Europe.

Variables	*n* (%)
Men	806 (50.7%)
Median age in years	34 (Q1=26; Q3=45)
Educational level	
Less than high school	98 (6.1)
High school	778 (48.9)
College degree	270 (17.0)
University degree	445 (28.0)
Employment status	
Part-time or full-time work	1122 (70.5)
Job seeking, unemployed, or disabled	177 (11.1)
Homemaker or retired	112 (7.0)
Full-time student	87 (5.5)
Other	93 (5.9)
Marital status	
Married or living with partner	955 (60.0)
Never married	556 (35.0)
Divorced or widowed	80 (5.0)
Children: yes	735 (46.2)
Patient-reported New York Heart Association assessment	
Class I	935 (58.8)
Class II	516 (32.4)
Class III	104 (6.5)
Class IV	36 (2.3)
Complexity of heart defect	
Simple	511 (32.1)
Moderate	763 (48.0)
Complex	317 (19.9)
Country	
Belgium	261 (16.4)
France	86 (5.4)
Italy	51 (3.2)
Malta	108 (6.8)
Norway	164 (10.3)
Sweden	435 (27.3)
Switzerland	251 (15.8)
The Netherlands	235 (14.8)

The performance of the respective national healthcare systems were graded on a three-grade scale for each of the 48 indicators (i.e. inadequate, moderate, good) and in line with the grading, scores were assigned (i.e. inadequate/not available = 1, moderate = 2, good = 3). In order to calculate the score of each subdomain, the scores assigned to each indicator were summed up. Afterwards, the subdomain scores were multiplied by fixed weight coefficients and added up to make the final country score. As data collection ran from 2013 to 2015, we chose to use the EHCI of 2015.

The EHI, which was published in 2008 and 2016, focuses specifically on the performance of care provided to patients with cardiovascular conditions in 30 European countries.[18] This index was chosen because adults with CHD are primarily treated in cardiovascular care settings. The EHI consists of a set of 31 healthcare system performance indicators, which are divided into four subdomains: (a) prevention; (b) procedures; (c) access to care; and (d) outcomes (Supplementary Table 2). Scores on subdomains and total score were calculated in a similar way as the EHCI. For the present study, we employed the EHI of 2016.

Statistical analyses

Demographic and medical background variables were calculated as median and interquartile range in the case of non-normally distributed continuous variables, and as absolute numbers and percentages in the case of categorical variables.

Multivariable and sensitivity analyses using general linear mixed models were used to estimate the association between the domains and total score of healthcare system performance (i.e. EHCI and EHI) and five PROs (i.e. perceived physical functioning, perceived mental health, psychological distress, health risk behaviour and quality of life). A two-level structured analysis was used, considering that patients were nested within countries. In the multivariable analyses, we controlled for patient characteristics (i.e. age, sex, educational level, employment status, marital status, patient-reported NYHA assessment and disease complexity) and unmeasured country differences (random effect). As all domains of the EHCI and EHI were analysed separately, a total of 60 multivariable analyses were performed. Hence, we adjusted for multiple testing by calculating false discovery rates and reporting Benjamini–Hochberg adjusted *P* values. The significance level of the false discovery rate was 0.05. In order to evaluate the robustness of the results, we performed sensitivity analyses in which we left out countries with an outlying value of more than two standard deviations (SD) from the mean on one of the subdomains of the EHCI or EHI.

Only patients for whom full data were available for all variables of interest were included in the general linear mixed models, as only a small proportion of patients had missing values for PROs (0.0–2.1%) and patient-related predictors (0.0–2.5%). The EHCI and EHI possessed complete data. Data analysis was performed using IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, NY, USA).

Results

Sample characteristics

A total of 1591 adults with CHD with full data from eight European countries were included in the study. The majority of patients were men (50.7%), had a moderate disease complexity (48.0%) and self-reported to be in NYHA class I (58.8%) (Table 1).

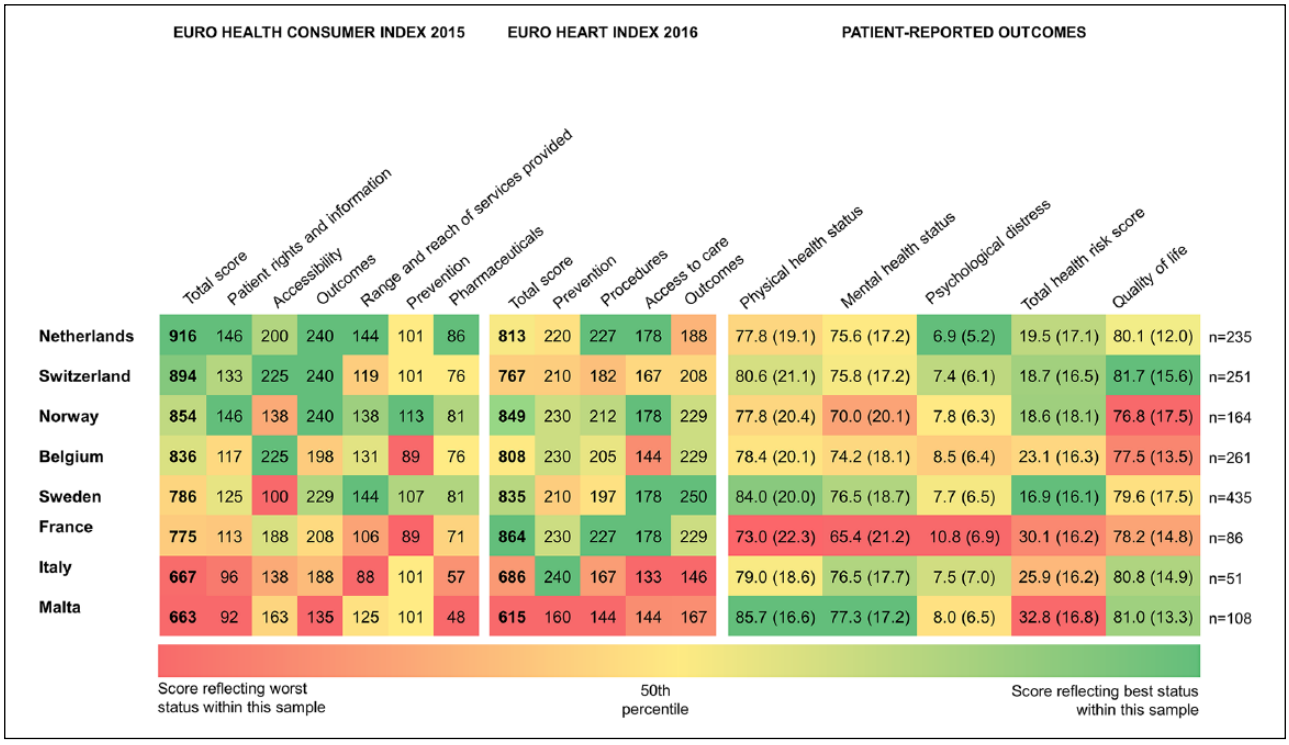

Figure 2. Distribution (heat map) of the patient-reported outcomes (PROs) and scores on Euro Health Consumer Index and Euro Heart Index of the included European countries. PROs are described as mean (standard deviation).

Healthcare system performance

Scores on the different domains of the EHCI and EHI for the respective participating countries are presented on the heat map of Figure 2. Looking at the performance of the healthcare system (i.e. EHCI), the healthcare system of The Netherlands was found to have the best total score, followed by Switzerland and Norway. Malta had the lowest total score. When looking at subdomains, Norway and The Netherlands gathered the highest score on 'patient rights and information'. The lowest waiting times were observed in Belgium and Switzerland. Best health outcomes were measured in The Netherlands, Norway, and Switzerland, whereas 'range and reach of services' was found to be best in The Netherlands and Sweden. Norway was leading when looking at indicators about prevention of chronic diseases. Finally, The Netherlands achieved best scores on consumption, financing and deployment of pharmaceuticals.

Regarding the performance of cardiovascular care and treatment (i.e. EHI) for the respective included countries, France had the highest total score, followed by Norway and Sweden. In line with the EHCI, the Maltese healthcare system performed lowest on cardiovascular care. When examining subdomains, Italy performed best on 'prevention for cardiovascular disease'. France and The Netherlands were ranked highest with respect to the subdomain 'quality and availability of procedures concerning cardiovascular disease'. Access to cardiovascular care was best in France, The Netherlands, Norway and Sweden. Finally, Sweden had the best outcomes for cardiovascular disease patients.

Patient-reported outcomes

PROs of this patient population were detailed on the heat map (Figure 2). Perceived physical and mental health scores were highest in patients from Malta. Patients from The Netherlands showed the lowest symptoms of psychological distress. Participants from Sweden had the lowest health risk scores, and patients from Switzerland achieved the best results on quality of life.

Association between healthcare system performance and PROs

Adjusting for patient characteristics, unmeasured country differences and multiple testing, the multivariable general linear mixed models showed that less risky health behaviours were associated with better scores on subdomains 'patient rights and information', 'outcomes', or 'pharmaceuticals', measured by the EHCI (Table 2). Furthermore, perceived physical health was associated with healthcare systems performing high on the prevention of chronic diseases, as assessed by the EHCI (Table 2). Components of

Table 2. Multivariable general linear mixed models with Euro Health Consumer Index and Euro Heart Index healthcare system performance domains as predictors of patient-reported outcomes, adjusted for patient characteristics and unmeasured country differences (n=1591).

	Physical health status	Mental health status	Psychological distress	Total health risk score	Quality of life
Euro Health Consumer Index					
Patient rights and information	0.01 (0.05)	−0.01 (0.04)	−0.04 (0.01)	−0.24 (0.06)	0.005 (0.04)
Accessibility	−0.04 (0.01)	−0.01 (0.01)	0.005 (0.007)	0.01 (0.04)	0.0006 (0.01)
Outcomes	0.01 (0.03)	−0.006 (0.02)	−0.02 (0.008)	−0.14 (0.02)	0.01 (0.02)
Range and reach of services provided	0.01 (0.05)	−0.002 (0.04)	−0.01 (0.02)	−0.15 (0.09)	−0.06 (0.04)
Prevention	0.31 (0.04)	0.13 (0.06)	−0.09 (0.03)	−0.38 (0.21)	0.04 (0.08)
Pharmaceuticals	−0.02 (0.07)	−0.05 (0.06)	−0.03 (0.03)	−0.37 (0.09)	−0.02 (0.06)
Total score	−0.007 (0.01)	−0.006 (0.008)	−0.004 (0.004)	−0.05 (0.01)	−0.0001 (0.008)
Euro Heart Index					
Prevention	−0.03 (0.04)	−0.05 (0.02)	−0.009 (0.01)	−0.10 (0.07)	−0.004 (0.03)
Procedures	−0.02 (0.03)	−0.05 (0.02)	−0.003 (0.01)	−0.08 (0.06)	−0.006 (0.03)
Access to care	0.05 (0.05)	−0.02 (0.04)	−0.02 (0.02)	−0.16 (0.09)	0.03 (0.04)
Outcomes	−0.001 (0.03)	−0.03 (0.02)	0.007 (0.01)	−0.07 (0.05)	−0.02 (0.02)
Total score	−0.003 (0.01)	−0.02 (0.008)	−0.0007 (0.004)	−0.04 (0.02)	−0.003 (0.009)

Values in table are estimates (standard error).
Colour-coding refers to significance of estimate after correction for multiple testing (Benjamini–Hochberg adjusted P value).
Physical and mental health status: higher scores reflect better perceived health.
Psychological distress: higher scores reflect more symptoms of depression and anxiety.
Total health risk score: higher scores reflect unhealthier behavior.
Quality of life: higher scores reflect higher quality of life.

NS	<0.05	<0.01	<0.001

the EHI were not associated with PROs in adults with CHD.

Because Malta had outlying values (>2 SD) on the EHCI subdomain 'outcomes' and the EHI subdomain 'prevention', we repeated these analyses while excluding the data from Malta. After correction for false discovery rate, the associations between EHCI subdomain 'outcomes' and PROs did not change, as again only the association between the subdomain 'outcomes' and the total health risk score was significant. Again, no significant associations were found between the EHI subdomain 'prevention' and PROs.

Discussion

We examined associations between components of the healthcare system performance and PROs in adults with CHD, in order to scrutinise further geographical differences in PROs that were previously reported.[10] Health risk behaviours of adults with CHD were found to be associated with the EHCI subdomains 'outcomes', 'patient rights and information' and 'pharmaceuticals'. Physical health status was associated with the EHCI subdomain 'prevention'.

The relationship between health risk behaviours and 'outcomes' is perhaps unsurprising because the EHCI subdomain 'outcomes' comprises indicators particularly relevant for patients with CHD, such as a decrease of cardiovascular disease deaths, decrease of stroke deaths and infant deaths.[17] It is well known that a heart-healthy lifestyle is associated with favourable health outcomes, both in the general and in clinical populations.[24]

The subdomain 'patient rights and information' pertains to the ability of a healthcare system to provide the patients with a status strong enough to be able to interpret information in an appropriate manner. Hence, a high score on 'patient rights and information' reflects the importance that is given to inform and instruct patients in particular countries. In its turn, this may have resulted in patients with higher patient activation, who are willing and able to take charge of their own health by performing good health behaviours.[25] Indeed, patient activation and empowerment have been shown to be associated with healthy behaviour.[26]

The EHCI subdomain 'pharmaceuticals' describes consumption, financing and access to drugs. It can be presumed that countries with good access and refunds for pharmaceuticals have good access and refunds for other healthcare services as well. Indeed, this might partly explain the association found between the EHCI subdomain 'pharmaceuticals' and health risk behaviours.

The association between perceived physical health and the EHCI subdomain 'prevention' is anticipated given that it is hoped that healthcare systems that focus on prevention would help individuals achieve better health status. Although our study showed an association between these distal concepts, future studies could perhaps add clarity about underlying mechanisms and possible confounders.

Subdomains of the EHCI that were not related to any of the PROs were 'accessibility of care' and the 'range and reach of services provided'. This suggests that the general accessibility of healthcare and a broad offer of public services in the respective countries may not reflect PROs in CHD. Moreover, healthcare system performance only seems to be of importance for physical wellbeing and health risk behaviours. No associations have been found with perceived mental health, psychological distress and quality of life.

Regarding the EHI, none of the subdomains were associated with PROs of adults with CHD. Even when excluding the outlying value of Malta on the EHI subdomain of prevention in sensitivity analyses, no significant association was found. As associations with EHI domains were expected, these results are surprising. To the best of our knowledge, this is the first time that the EHI has been used for research. In order to be able to interpret the absence of associations, the relevance of the index for congenital as well as for acquired heart diseases should be investigated.

Methodological issues

First, we performed an explorative ecological cross-sectional study. Hence, no conclusions in terms of the direction of effects or causality can be drawn. Indeed, the field of PRO research would benefit from longitudinal assessment.[27] Moreover, we could not assess the underlying mechanisms, which is why we are unable to provide explanations of observed associations.

Second, we measured the components of healthcare system performance using the EHCI and the EHI.[17, 18] These measures deliver very detailed information on the subdomains of healthcare system performance of the participating countries. Although some individuals have criticised these performance measures on their transparency, methodology and validity,[28, 29] we are unaware of any better measures of components of healthcare system performance.

Third, data of healthcare system performance were gathered on a country level and PROs were gathered on a patient level. However, multilevel analyses were performed to control for unmeasured country differences and to consider that patients are nested in countries.

Fourth, it is difficult to tell to what extent our findings can be generalised. Although the differences in demographic, clinical and health status characteristics between participants and non-participants appeared to be small,[30] the present study included eight European countries, all of which were high-income countries. It would be interesting to include middle-income European countries (e.g. Albania, Croatia, Macedonia and Kosovo) in future studies and to investigate the effect of the general healthcare system performance on PROs beyond the European borders. Moreover, the unequal division of participants across the countries might also have influenced the results, as some countries have been overrepresented with regard to other countries. Furthermore, patients who received the questionnaire were almost all under follow-up in a CHD/adult CHD centre and it could be that patients who are not under follow-up have different characteristics. Finally, it remains unknown whether our results in adults with CHD can be generalised to other patient populations. CHD, as a sample case, represents a broad spectrum of mild, moderate, and complex chronic diagnoses. To increase the generalisability and transferability of findings, it would be interesting to add a healthy control group or general population normative data.

Generally, the findings of this study provide information on which domains of the healthcare system performance are of importance for particular PROs of adults with CHD. However, further research is needed in order to be able to give concrete advice for policy-makers or for clinical practice. We hope that our present findings may be a trigger for future research to fill these knowledge gaps.

Conclusion

The current study showed that several features of healthcare system performance are associated with perceived physical health and health risk behaviours in adults with CHD. More specifically, the EHCI subdomains 'outcomes', 'prevention', 'patient rights and information' and 'pharmaceuticals' were associated with these two PROs, above and beyond patient characteristics. Before recommendations for policy-makers can be conceived, future research should further investigate the impact of the healthcare system performance on outcomes of adults with CHD using different indices and should examine the underlying mechanisms of the associations found.

Implications for practice

- 'Outcomes', 'prevention', 'patient rights and information', and 'pharmaceuticals' are aspects of general healthcare system performance that may translate into better patient-reported outcomes of persons with congenital heart disease.
- Policy-makers should safeguard healthcare system factors that are protective for patient outcomes.
- Countries that score low on particular domains of the healthcare system performance could consider investing in these features in order to improve outcomes of specific patient populations.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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Supplementary material

Supplementary material for this article is available online.

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